

SHARED DECISION MAKING

Viewer's Guide

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in collaboration with

The Center for Practice Innovations



The viewer guide and corresponding materials were developed by the Center for Practice Innovations in collaboration with Dr. Patricia Deegan.

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Making the most of this Viewer's Guide

The Viewer's Guide is a companion piece to the Shared Decision Making videos. We recommend using the self quizzes, discussion questions and additional resources to deepen your understanding of the practice of shared decision making. The answers to the quiz questions can be found in the Appendix.

Videos	Run Time
Introduction & Overview	7:29 min
Chapter 1 – What is Shared Decision Making?	8:02 min
Chapter 2 – Shared Decision Making in Behavioral Health	12:03 min
Chapter 3 – Why Shared Decision Making with Young People?	10:17 min
Chapter 4 – Decision Aids	10:55 min
Chapter 5 – Doing Shared Decision Making	9:36 min
Chapter 6 – You Are Part of the Team	8:21 min

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Introduction & Overview



For young people and their families, first episode psychosis can be a time of turmoil, fear and confusion. The work of specially trained First Episode Psychosis (FEP) Teams can help young folks navigate through this tough time, get their lives back on track and achieve personal recovery goals such as school, work, friendship and romance.

Shared decision making is one of the core concepts underlying the work of OnTrack teams. Shared decision making reflects the values of collaboration, engagement, self-determination and respect that infuse every aspect of what teams do.

In this video series you will learn that shared decision making is a person centered practice that supports individuals and their families in having a voice and a choice in treatment and care. It's a practice that should be used routinely by all members of your team including team leaders, IPS specialists, recovery coaches, and team nurses and psychiatrists.



This series of videos and the Viewer's Guide were developed specifically for OnTrack programs. The videos use a rapid e-learning format. Each video is 8-12 minutes in length and can easily accommodate the busy schedules of the team. There's no need to watch all of the videos at once.

It is recommended that you watch the videos in consecutive order. It's also recommended that you use the Viewer's Guide with each video. In the Viewer's Guide you will find self-quizzes to test your understanding, discussion questions and more resources on the practice of shared decision making.

Think carefully about the most efficient and effective way to use this resource. One method might be to ask each team member to view a video per week. Then, use 20 minutes of a regularly scheduled meeting to complete the self quiz and discuss the questions in the Viewer's Guide. Spend some time thinking about what might work best for your team.

Video Overview

There are six videos or chapters. Each video builds on the previous ones, so it's important to view them consecutively.

- Chapter 1. **What is Shared Decision Making?:** In this chapter, shared decision making is broadly defined as we explore its origins in general medicine. The evidence to support the practice of shared decision making is discussed and the ethical imperative that underscores its use is presented.
- Chapter 2. **Shared Decision Making in Behavioral Health:** In this chapter, we narrow the scope from shared decision making in general medicine, to shared decision making in behavioral health. We discuss the question of the relevance of shared decision making for people diagnosed with serious mental illness, especially in relation to decision capacity. We also explore various crossroad and continuing care decision points encountered in routine work. We place special emphasis on the fact that shared decision making is not just for

decisions about medications. Shared decision making can also be used at other decision points such as deciding to return to work or school, deciding to move away from home, deciding when or if to disclose psychiatric history in a new relationship and the like.

- Chapter 3. **Why Shared Decision Making With Young People:** In Chapter 3, we raise the question of why shared decision making is important for teams working with young people and their families. In particular, we explore the importance of a developmental approach and how to involve families in shared decision making, especially when working with teens.
- Chapter 4. **Decision Aids:** Decision aids are specially crafted tools that support shared decision making. They can be used during appointments or prior to consultations with the team. Links to various decision aids for your use are included in this Viewer's Guide.
- Chapter 5. **Doing Shared Decision Making:** In Chapter 5, we look at the specifics of how to do shared decision making. We learn how to set up a lending library and other techniques for building a programmatic infrastructure to support shared decision making. We also present a three-part method to support shared decision making that includes Choice Talk, Option Talk and Decision Talk. Shared decision making can be done in the office, but it can also be done when working with folks out in the community.
- Chapter 6. **You are Part of the Team:** Chapter 6 is a bit different than the others. Chapter 6 was created specifically for individuals and their supporters or family members. It explains why shared decision making is important and what to expect from the team. Clearly, being asked to collaborate in decision making will be a different kind of experience for many people. This video will help folks better understand the importance of being a member of the decision making team. Although this video was made for individuals and families, it is recommended that the team study it as well.

Of course, studying the videos and the Viewer's Guide is just the beginning. The ongoing task is to practice shared decision making each day and to refine your skills over time. Learning to notice decision points in all their many forms is especially challenging when first starting to practice shared decision making. Time management can also be a challenge when first practicing shared decision making during time-limited consultations. Be sure to share your progress and challenges with team members. The whole team can learn and progress together.

When asked, many clinicians say, "I already do shared decision making". Indeed, many of us use some degree of collaboration and consensus building in our practice. However, after studying this video training series, I think you will agree that shared decision making is a more rigorous and thorough practice than most realize. Shared decision making is a new and respectful way of working with people. It can be combined with other practices such as motivational interviewing to help your team provide truly person centered care to young people and their families.

SELF QUIZ - INTRODUCTION

Q. *Is the following statement true or false?*

- **Shared decision making is primarily for medication decisions and it is mostly psychiatrists who will use this practice in the work of OnTrack teams.**

Q. *Is the following statement true or false?*

- **Shared decision making is a unique practice and should not be combined with other evidence based practices such as motivational interviewing and family psycho-education.**

Q. *Is the following statement true or false?*

- **Most person centered clinicians already practice shared decision making.**

DISCUSSION QUESTIONS - INTRODUCTION

Use the following questions/statements to guide your discussion:

- Discuss your team's plan for using the shared decision making videos and Viewer's Guide. How will you ensure access to the videos? Will you watch the videos as a group or individually? When will you consult the Viewer's Guide? How might you make the additional resources available to the group? Remember, we do not recommend watching all the videos at once.
- It is important to practice shared decision making. How will your team get started practicing shared decision making? Will there be a special time to report back to the team on the experiences you are having with shared decision making in the field. How can you learn from each other?
- Sometimes there is resistance to the practice of shared decision making because it challenges certain assumptions. What assumptions and practices does shared decision making disrupt? Do you anticipate discomfort with the practice of shared decision making? How might you address this?

SUGGESTED RESOURCES - INTRODUCTION

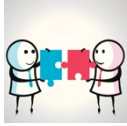
Here is a listing of resources for further exploration on the topics covered in this chapter:

- **A vision for patient and family engagement in healthcare:** This is an introductory, 5 minute video sketching a vision for healthcare delivery that includes individuals and their families at the center of the care team. (<http://patientfamilyengagement.org/vision>)
- **What is medical shared decision making:** This is a short, 1.5 minute overview of shared decision making and why it's important. (<https://www.youtube.com/watch?v=SxM6GnGE12Q&feature=youtu.be>)
- **CollaboRATE:** As your team adopts shared decision making, it will be helpful to measure how well you are doing. CollaboRATE is a 3-item, patient rated scale with good psychometric properties. There is also a version for parents. This scale is available under a Creative Commons License which means you can use it (but not alter it). (<http://www.collaboratescore.org/collaborate.html>)

Notes: _____

Chapter One:

What is Shared Decision Making?



Shared decision making is a collaborative process that allows individuals and their care teams to make treatment decisions together, taking into account the best scientific evidence, as well as individual values and preferences.

Pat Deegan first learned about shared decision making at the Dartmouth Hitchcock Medical Center in New Hampshire. Here's how it works:

Imagine that you or a loved one were newly diagnosed with breast cancer. Rather than immediately meeting with an oncologist to discuss treatment options, you would first go to the Center for Shared Decision Making, located on the first floor of the medical center. There you would find a library of carefully crafted decision aids and a nurse to introduce you to them. Decision aids are interactive tools that would help you understand your condition, your treatment options, including the option of watchful waiting, as well as the benefits and risks of each option. Importantly, the decision aid would also help you think about your preferences and values, and to focus on how various options might affect the quality of your life.

Using a decision aid, you would learn that mortality rates for women with early stage breast cancer are relatively the same whether they choose lumpectomy (removing just the cancerous tissue) or mastectomy which involves removing the entire breast. So even though the impact of both treatments on the cancer are about the same, the 2 options are very different in terms of quality of life. If asked, some women will feel strongly about breast preservation. Others will not. That means that neither treatment is the right treatment for *every* woman. The decision to have lumpectomy or to have a breast removed is what is called a preference sensitive decision. Preference sensitive decisions require, from an ethical perspective, that a woman's preference be taken into account.

Decision aids help prepare a woman to participate in shared decision making with her oncologist. She can bring the decision aid home and review it with loved ones. She can make notes, write down her questions and indicate her decisional leaning, or how sure she is feeling about which path to take. Finally, when she is ready, she can meet with the oncologist and together they can make the best decision about how to proceed. Rather than persuading the woman to choose one option over another, the oncologist trained in shared decision making will strike a stance of equipoise, provide more information if required and help support the woman's decision making process.

When Pat first saw shared decision making in action she said to herself, "That's the kind of clinical care I would want". Chances are, you are thinking the same thing. There are at least 4 reasons why the practice of shared decision making is compelling:

1. Shared decision making is a compelling practice because decisions about treatment are not just medical decisions. Decisions about treatment are also personal decisions that affect us and those we love. Shared decision making shifts the focus from “what is the matter”, to “what matters to you”. What matters to us, our values and preferences, must be a central part of the decision making process.
2. Shared decision making is compelling because for many medical conditions, scientific evidence is not definitive, it is incomplete or it is open to more than one interpretation. In such situations, there is an ethical imperative to include people in the decision making process. An example might be when a woman in treatment for bipolar disorder becomes pregnant. Should she continue to take mood stabilizing meds? Should she discontinue meds? The scientific evidence to support one right choice is simply not available at this time. The data are equivocal and in such cases, there is an ethical imperative to involve the woman in shared decision making.
3. Shared decision making is compelling because in many instances, there is more than one right option as we saw in our vignette on early stage breast cancer. In situations where there is more than one “right” option, it is important to match individual preference with choice of treatment. If we assume we can predict peoples’ preferences, then we are at risk of making a preference “misdiagnosis.” For instance, physicians predicted that 71% of women would choose breast preservation as a top priority. But what do you think women with breast cancer said? Only 7% agreed that breast preservation was a top priority¹. In truth, preference misdiagnosis happens all too frequently. Shared decision making prevents preference misdiagnosis and helps us get the right treatment for the right person.
4. Shared decision making is a compelling practice because it is perfected informed consent. In everyday practice there is significant drift in the practice of obtaining informed consent. Shared decision making, especially when supported by decision aids, is a higher standard and for that reason is increasingly being adopted by states and recommended in federal policy.

What's the Evidence?

There is good evidence to support the practice of shared decision making. We know that when shared decision making is combined with the use of decision aids²:

- People are more knowledgeable about the risks and benefits of treatment options
- People have less decision regret and are more satisfied with their choices
- People are more activated and engaged in their care



Research also shows that shared decision making holds the potential of helping to reduce health disparities, especially for people with low health literacy. Finally, people who are involved in shared decision making tend to be more conservative in their choice of treatments, resulting in lower healthcare costs.

¹ Lee CN, Dominik R, Levin CA, Barry MJ, Cosenza C, O'Connor AM, Mulley AG Jr, Sepucha KR (2010). Development of instruments to measure the quality of breast cancer treatment decisions. *Health Expectations*, vol 13, no 3, pp 258–72. doi:10.1111/j.1369-7625.2010.00600.x

² Stacey D, Légaré F, Col NF, Bennett CL, Barry MJ, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thomson R, Trevena L, Wu JHC. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2014, Issue 1. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431.pub4

It is important to note that not every clinical situation requires shared decision making. For instance, shared decision making is inappropriate if a person arrives in the emergency department with an acute, life threatening condition. Similarly, when a person is severely compromised through acute intoxication or delirium, shared decision making is not the best course. Shared decision making also requires decisional capacity. If there is a clear gold standard of treatment in which the scientific evidence unequivocally supports one best option, informed medical decision making, but not necessarily shared decision making, is recommended. An example might be use of insulin for Type-1 diabetes.

Shared decision making is used for social decisions, not just medical decisions. For instance there are decision aids for end of life care, choice of assisted living and when to stop driving.

SELF QUIZ – CHAPTER 1

Q. *Which of the following statements is true?*

- A. **Persuasion has a limited place in the shared decision making process**
- B. **Shared decision making should be used in situations where there is more than one right choice**
- C. **Decision aids are patient education aids**
- D. **Decision aids are best used in clinic settings, such as shared decision making centers**
- E. **Therapists and case managers have fewer opportunities to practice shared decision making than medical practitioners**

Q. *Which of the following outcomes has not been found in studies of shared decision making?*

- A. **Lower levels of satisfaction**
- B. **Higher levels of patient engagement**
- C. **Lower healthcare costs**
- D. **Less decision regret**
- E. **Reduction in preference misdiagnosis**
- F. **All of the above**

Q. *Which of the following statements is inaccurate?*

- A. **Shared decision making is an ethical imperative in all situations in which individuals are faced with a medical decision**
- B. **When a woman on mood stabilizing medications becomes pregnant, the decision to use/not use medications is a preference sensitive decision**

- C. **Shared decision making should be used when someone has an acute life-threatening condition**
- D. **Shared decision making is perfected informed consent**
- E. **Decision regret is typically higher when decision aids are unavailable**

DISCUSSION QUESTIONS – CHAPTER 1

Use the following questions/statements to guide your discussion:

- Do you wish that shared decision making was offered in the healthcare settings where you receive services? Explain.
- Have you ever experienced shared decision making in a healthcare setting? Conversely, have you ever wished you had more of a voice and a choice in your treatment?
- Have you ever made a preference misdiagnosis with someone you work with?
- Have you been in a situation where a team member made a preference misdiagnosis? Explain?
- If you could turn back time, what could have been done differently to prevent the preference misdiagnosis?
- Most clinicians value a collaborative, person-centered relationship with the folks they work with. How is shared decision making similar to how you collaborate with individuals currently?
- How is shared decision making different than informal collaboration?

SUGGESTED RESOURCES – CHAPTER 1

Here is a listing of resources for further exploration on the topics covered in this chapter:

- **Shared Decision Making in Three Words** (<http://youtu.be/rs8MyqHGkFM>): In this 1 minute video, people in the medical field are challenged to describe shared decision making in just three words. Can you do it too?
- **Kate Makes a Shared Decision** (<http://youtu.be/fp-BvMA3Dsg>): This 6 minute video follows one individual as she navigates a diagnosis of kidney failure through the use of decision aids, and shared decision making.
- **Framework for teaching and learning informed shared decision making:**
(<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1116602/>) This paper outlines a framework for putting shared decision making into practice at your organization.

- **Stop the silent misdiagnosis: Patients preferences matter:**

(<http://www.bmj.com/content/345/bmj.e6572>) This article underscores the importance of shared decision making, patient preferences and the danger of preference misdiagnosis.

[illegible]

Chapter Two: Shared Decision Making in Behavioral Health

Although shared decision making has its roots in medicine, the practice is migrating into behavioral health. In fact, the National Academy of Sciences has cited shared decision making as one of 10 rules to guide the redesign of mental health and substance abuse care in the 21st century. In this chapter, we will learn how the principles of shared decision making are a good fit for behavioral health.

Preference Sensitive Decisions

Those of us diagnosed with psychiatric conditions face many decisions about treatment on our journey of recovery. Perhaps the most frequently encountered decision point, are those about using psychiatric medications. Decisions about psychiatric medications meet all the criteria for being preference sensitive decisions. That is:

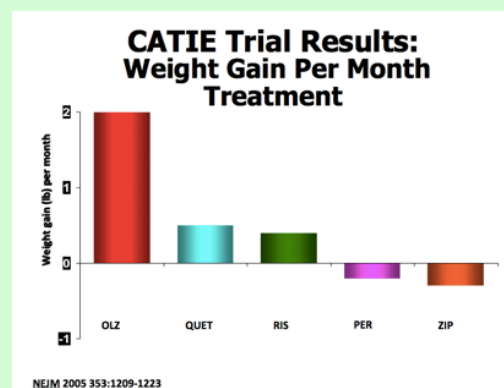


- There is more than one reasonable option when considering the use of psychiatric medicines
- Psychotropics within a class have similar effectiveness but different benefit and risk profiles
- Data to support one psychotropic agent in a class over another is equivocal, incomplete, and often open to interpretation.

Because decisions about psychiatric medicines are preference based decisions, there is an ethical imperative to involve people in a deliberative decision making process³.

Consider this set of results from the CATIE study (NIMH Clinical Antipsychotic Trials of Intervention Effectiveness).

Along the X axis we see 5 different antipsychotic medications: olanzapine, quetiapine, risperidone, perphenazine and ziprasidone. On the Y axis we see the amount of weight gained per month. Although these five medications were found to be comparably effective in terms of symptom relief, they varied significantly for risk of weight gain. Choice of antipsychotic agent is a classic preference sensitive decision. In order to avoid preference misdiagnosis, clinicians must include individuals in making the choice about using antipsychotic and other psychiatric medications.



³ Lieberman J, Stroup TS, McEvoy JP, et al (2005). Effectiveness of antipsychotic drugs in patients with chronic schizophrenia. New England Journal of Medicine 353:1209–1223

Remember, decisions about treatment are not just psychiatric decisions. Decisions about treatment are also personal decisions. For preference sensitive decisions, it is not enough for clinicians to make decisions on behalf of individuals or to actively persuade them. The choice to expose oneself to medication related risks such as weight gain, sexual dysfunction, serotonin syndrome, tardive dyskinesia, agranulocytosis, cardio-metabolic syndrome, hair loss, etc. – these are decisions that require shared decision making. In this way, preference misdiagnoses are avoided.

The choice to use an antipsychotic can be considered a preference sensitive decision and shared decision making applies. Antipsychotics can be very helpful tools in learning to effectively manage psychotic symptoms. Many studies have established the effectiveness of antipsychotics. And there can be significant risks associated with not using antipsychotics.

However, these medications also have significant risks. There is considerable debate in our field about dosing and duration, and the role of antipsychotics in treatment of first episode psychosis. Further, some people recover without medications while others do not benefit from antipsychotic medications.

What we need is a robust decision aid for young people and their families to support shared decision making about the use of antipsychotics. Until such time, we must do our best to help individuals and their families understand the benefits and risks of using, or not using antipsychotics. We must lay out all the options for treatment and help people understand their values and what matters to them. Learning to use psychiatric medication optimally in one's recovery process is a journey that takes time. Shared decision making builds the therapeutic alliance and keeps clinician goals aligned with those of the individual and family.

Social Decision Points

In addition to medical decision points, there are other types of decision points in behavioral health. For instance there are social decision points such as:

- Deciding to return to work or school
- Deciding to apply for SSI
- Lifestyle modification decisions such as beginning an exercise program
- Deciding when to disclose a psychiatric diagnosis at work, when dating, at school, etc.
- Decisions about representative payee and money management arrangements



All of these social decision points are preference sensitive decisions and require shared decision making if they are to be addressed within psychiatric treatment.

Crossroad and Continuing Care Decision Points



Additionally, in behavioral health there are both crossroad decision points and continuing care decision points. A crossroad decision point is characterized by decisions that can't be "undone". Examples of crossroad decision points might include the decision to have ECT or the decision to use a new medication. The use of psychiatric meds during pregnancy, the decision to have psychosurgery for intractable OCD, the decision to go off SSI and return to work, and the decision to disclose a diagnosis to an employer are other examples of crossroad decision points.

Another group of decision points in behavioral health can be characterized as continuing care decision points. Continuing care decision points often involve making adjustments in the course of an agreed on treatment path. For instance, once a decision to use a medication has been made, treatment is often adjusted and refined. There are ongoing decisions to continue, reduce or raise dosages. Similarly, once supported employment has been chosen, there may be a number of ongoing decisions that must be made in order to match individuals with the right job.



Shared decision making can be used for both crossroad decisions as well as continuing care decisions. However, formal decision aids are typically developed for crossroad decisions. As we will see later, other complimentary decision support techniques can be used for shared decision making at continuing care decision points.

Acuity of Symptoms

The issue of acuity of symptoms and consequences of waiting can be an important consideration in applying shared decision making. Sometimes it is desirable for decisions to be made more quickly, for example when an individual is experiencing a great level of distress. In other situations we have the luxury of more time to support deliberation. For instance, consider a young man who has troubling and distressing symptoms and has decided to take an antipsychotic medication. He and his doctor are using shared decision making to decide which medication to take. Since he is suffering with symptoms, it would be better if he could decide more quickly which medicine to take in order to try to get some relief quickly. This does not mean shared decision making is not used; rather, it is done with the awareness that there are pros and cons to taking more time to decide.

Decisional Capacity

The issue of decision capacity is important in any discussion of shared decision making, but especially when applied to behavioral health. Studies have shown that people diagnosed with schizophrenia have higher preferences for involvement in treatment decisions than general medical patients. However, do people with psychiatric conditions have decision capacity?

The CATIE trial⁴ helps us understand that for most of the 1,158 research participants with psychosis, decision capacity remained stable or improved over the course of the 18-month study. Four percent (4%) of

⁴ Stroup TS, Appelbaum PS, Gu H, Hays S, Swartz MS, Keefe RSE, Kim S, Marder DR, Boshes R, McEvoy JP, Lieberman JA. (2011). Longitudinal consent-related abilities among research participants with schizophrenia: Results from the CATIE study. *Schizophrenia Research*. 130(1-3): 47-52.

the participants fell below criteria for consent-related decision capacity during the study. One fourth of the participants had a period where decision capacity worsened, but did not fall below capacity to consent to participation.

What we know about the decisional capacity of individuals experiencing first episode psychosis is limited. It is possible that young people who are experiencing psychosis for the first time may have more difficulty appreciating the extent to which some symptoms may be having an impact on their decisions. Nevertheless, lack of capacity should never be assumed. I think it's fair to say that we can have relatively strong confidence in people's capacity to participate routinely in shared decision making. There will be times when individual decision capacity may fluctuate. In such cases psychiatric advanced directives can be helpful in safeguarding individual preferences until capacity is regained. With the help of carefully crafted decision aids and clinicians' trained in the practice of shared decision making, we should set the goal that all individuals, and their supporters, will participate.

Compulsory Treatment

At this point you may be wondering if shared decision making is applicable in situations of compulsory court ordered treatment. In such situations courts establish certain non-negotiables such as adherence to long acting injectable medications. I think the answer is that within the non-negotiable zone there is plenty of room for respectful collaboration and shared decision making. Many of the decision support tools we will review later have applicability in such situations.

SELF QUIZ – CHAPTER 2

Q. Which of the following scenarios reflect a preference sensitive decision?

- A. The decision to use or not use psychiatric medicine
- B. The decision to undergo ECT
- C. The decision to use an antidepressant medication with fewer sexual side effects over another
- D. The decision to return to school
- E. All of the above

Q. Is the following statement True or False?

- Shared decision making does not apply to people under a court order for compulsory treatment.

Q. Which of the following scenarios demonstrates a crossroad decision point?

- A. The decision to increase the dose of an antidepressant
- B. The decision to use psychiatric medications during pregnancy

- C. The decision to complete an application for a job
 - D. The decision to take a full course load for fall semester, or to take one class that semester.
 - E. 1 and 2
-

Q. *Is the following statement True or False?*

- **Someone who is experiencing acute positive symptoms of psychosis can never participate in shared decision making due to decision incapacity.**

DISCUSSION QUESTIONS – CHAPTER 2

Use the following questions/statements to guide your discussion:

- Have you, or a loved one, faced a preference sensitive decision? If you are comfortable sharing, what was the decision? Did the healthcare provider do anything to help you or your loved one have a voice and a choice in making the decision?
- Can you think of a time you worked with someone who was facing a preference sensitive decision?
 - What was the decision?
 - What did you do to support them?
 - What, if anything, would you do differently?
- Assuming there are no health conditions to contraindicate treatment, do you think that every young person diagnosed with psychosis should receive a trial on an antipsychotic? Explain your position.
- Almost everyone would agree that choice of medication within a class of medications is a preference sensitive decision. But, assuming decision capacity, is the decision to use or not use psychiatric medication a preference sensitive decision? What are your thoughts?
- You are a professional working on an OnTrack team. If your young relative developed a psychosis, how would you, personally, advise them?
- Make a list of the risks a young person would face if they chose to not use an antipsychotic medication. Reference reliable data from systematic reviews to reinforce your facts.
- Make a list of the risks a young person would face if they chose to use an antipsychotic. Reference reliable data from systematic reviews to substantiate your facts.

SUGGESTED RESOURCES – CHAPTER 2

Here is a listing of resources for further exploration on the topics covered in this chapter:

- **An important study on long-term outcomes of treatment with antipsychotics with young people** (<http://archpsyc.jamanetwork.com/article.aspx?articleid=1707650>) and **NIMH Director Thomas Insel's reflection** on it (<http://www.nimh.nih.gov/about/director/2013/antipsychotics-taking-the-long-view.shtml>).
- **Psychiatric Advanced Directives can be helpful in situations of decision incapacity:** This is state-of-the-art resources – videos and forms – about how to help those who are experiencing decision incapacity have a voice and a choice in decisions that affect their lives. (<http://www.nrc-pad.org/>)
- **The Affordable Care Act (ACA) calls for shared decision making:** Learn more in this commentary in the New England Journal of Medicine. (<http://www.nejm.org/doi/full/10.1056/NEJMp1209500>)

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Chapter Three:

Why Shared Decision Making with Young People?



Shared decision making is important when working with adolescents and young adults because it helps them develop decision making skills as well as other skills needed for being an active member of the care team. It insures they will have a voice and a choice in decisions that affect their lives.

In this chapter, we will explore how shared decision making is relevant for teams that specialize in supporting the recovery of young people with first episode psychosis.

A Reflection from Pat Deegan

When I was 17 years old I was diagnosed with schizophrenia. I was told that I had a chronic disease and that I would never be well. I was told to take high dose antipsychotic medications for the rest of my life and to avoid stress.

As a young person, the prognosis of a life as a chronic mental patient was devastating to my identity. For many years my psychiatric diagnosis took on a master status, both defining and delimiting my sense of self. The prognosis of doom eclipsed my future, leaving me hopeless with no pathway into the future that I wanted for myself. Instead, what loomed before me was an endless parade of hours and days, lost in a cloud of cigarette smoke, staring into space and doing nothing. In many respects, the despair I experienced was more disabling than the disorder.

We don't have to repeat this terrible mistake.

Recovery is Real

When we work with young people, we must communicate that recovery is real and that there is hope for a full and meaningful life after a diagnosis.

One way we can communicate hope is through the practice of shared decision making.

When using shared decision making, we invite young people to consider their options and to reflect on what matters to them. In effect, we invite them to consider an array of possible futures. And when there are pathways into possible futures, there is hope for recovery.

For example, when using shared decision making to explore school options, a young person must begin to imagine a variety of possible futures, such as taking an English Composition course at a local community

college or doing an HVAC apprenticeship at the local technical school. Similarly, when using shared decision making to explore medication tradeoffs, a young person might imagine a future of not taking medicine but living with symptoms, or taking medicine but living with side effects.



Skill Development

In addition to conveying hope for a meaningful future through exploration of options, the practice of shared decision making also helps young people develop skills that will help them successfully navigate behavioral health services in the future:

- Invites young people to speak up during consultations. This helps develop self advocacy skills.
- Encourages young folks to engage as active partners with the care team. This is important because increased engagement is associated with better health outcomes.
- Helps people feel respected because they have a voice and a choice in their care.
- Helps people feel more in control, thereby supporting the emerging autonomy and self-direction of young people.

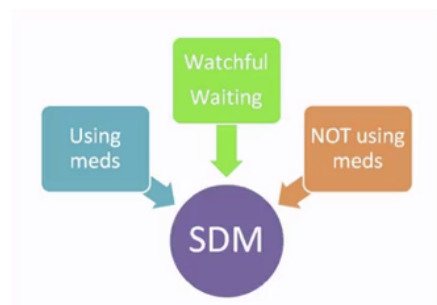
Medication Discontinuation and Watchful Waiting

There is another important benefit of shared decision making when used by teams serving young people with early psychosis. Shared decision making helps the team work more collaboratively during periods of medication discontinuation.

Coming to the decision to use or not use psychiatric medicine is typically a long and complex journey that involves trying medications, making trade-offs and sometimes even rejecting meds.

The notion of compliance and non-compliance oversimplifies the important deliberations that occur as young people grapple with the pros and cons, and benefits and risks of using psychiatric medicine.

Unlike the head-butting that so often characterizes the compliance/non-compliance discussion, shared decision making is a respectful way of walking with young people on their journey to discover if and how medicine will support their recovery. It does this by opening a third important option between using medicine and not using medicine. This third option is called watchful waiting.



When a young person is choosing not to use psychiatric medications, the team can introduce the option of *watchful waiting*. Putting a time limit around the period of watchful waiting can be helpful. For instance, the shared decision might be to reduce a dosage or discontinue a medication for a month and then check back in to assess how things are going.

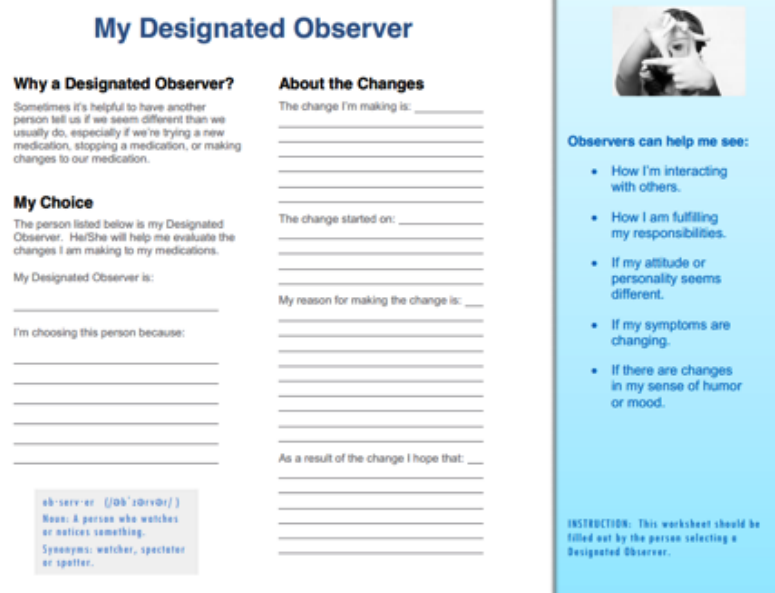
Instead of “doing nothing” during a period of med discontinuation,

the young person and the team can actively monitor what happens during a period of watchful waiting.

- Do symptoms get worse, improve or remain the same?
- Do relationships get more stressful, improve, or stay the same?
- What happens to the young person's ability to keep up with responsibilities during a period of watchful waiting?

A symptom tracking calendar can help organize these observations.

Teams can encourage the young person to designate a trusted friend or family member who is willing to share observations during the period of watchful waiting. Here is the My Designated Observer Worksheet.



The worksheet is titled "My Designated Observer" in blue. It is divided into two main columns. The left column contains sections: "Why a Designated Observer?" (explaining the purpose), "My Choice" (for selecting an observer), and a definition of "observer" with synonyms. The right column contains sections: "About the Changes" (for describing the change, its start date, and reasons), "Observers can help me see:" (a bulleted list of things to observe), and an "INSTRUCTION" at the bottom. The form includes numerous lines for handwritten input.

My Designated Observer

Why a Designated Observer?
Sometimes it's helpful to have another person tell us if we seem different than we usually do, especially if we're trying a new medication, stopping a medication, or making changes to our medication.

My Choice
The person listed below is my Designated Observer. He/She will help me evaluate the changes I am making to my medications.

My Designated Observer is: _____

I'm choosing this person because: _____

About the Changes
The change I'm making is: _____

The change started on: _____

My reason for making the change is: _____

As a result of the change I hope that: _____

Observers can help me see:

- How I'm interacting with others.
- How I am fulfilling my responsibilities.
- If my attitude or personality seems different.
- If my symptoms are changing.
- If there are changes in my sense of humor or mood.

INSTRUCTION: This worksheet should be filled out by the person selecting a Designated Observer.

observer (/ˈɒbzərvər/)
Noun: A person who watches or notices something.
Synonyms: watcher, spectator or spotter.

On the front, the young person can designate who they want in the role of observer. On the back of the worksheet, there is a template for the Designated Observer to share observations about symptoms, use of alcohol or drugs, ability to keep up with responsibilities, etc.

Family Involvement and Developmental Considerations

There are two other important considerations when using shared decision making with young people. The first is that cognitive processes associated with decision making are still developing in younger adolescents. The second related factor is that family or guardians often attend appointments with minors, leading to what is called triadic decision making or patient-provider-parent triads.

The literature on shared decision making with young people and family members is sparse when compared to what we know about adults⁵. The literature we do have suggests the following⁶:

⁵ Lipstein EA, Dodds CM, Lovell DJ, Denson LA, Britto MT (2014). Making decision about chronic disease treatment: a comparison of parents and their adolescent children. Health Expectations, 1-11.

⁶ Knapp C, Madden V, Feeg V, Huang IC, Shenkman E (2008). Decision making experiences of adolescents enrolled in children's medical services network. http://www.floridahealth.gov/alternatesites/cms-kids/home/resources/documents/adolescent_sdm.pdf

- Adopting a developmental perspective on decision making is prudent. As young people develop autonomy in other areas of their lives, they will seek increased autonomy in healthcare decisions as well. However, despite their growing autonomy, several studies of young people with long-term health conditions have found that parental involvement in decision making is still viewed as desirable by many.
- Young people want to be involved in decision making, even if they do not make the final decision. Compared to decisions about surgery, young people have a much higher preference for involvement in decisions about medicine, including whether or not to use it, route of administration, dosing and the like.
- In qualitative studies young people complain of being left out of decisions or being talked about like they are not even in the room. It is important to direct comments and share information with young people and to solicit their opinions, preferences and thoughts, even when parents are in the room.
- Parents sometimes try to limit information, especially about the risks of treatment. Young people with health conditions want information and are interested in talking with other young people who share similar life challenges. Use of the internet to gather information should be supported and teams should help young folks access credible information and decision aids when possible.
- When it comes to factors that influence decision making, data suggest that parents tend to focus on long term risks and outcomes. However, young people tend to focus on short term quality of life factors, particularly side effects.

Ottawa Family Decision Guide
For Families Facing Tough Health or Social Decisions

1. Clarify the decision.

What decision do you face?

What is your reason for making this decision?

When do you need to make a choice?

How far along are you with making a choice?

☐ Have not thought about the options ☐ Close to making a choice
☐ Thinking about the options ☐ Already made a choice

2. Explore the decision.

Knowledge List the options and main benefits and risks you already know.

Values Use stars (*) to show how much each benefit and risk matters to you. 5 stars means that it matters "a lot". No stars means "not at all".

Certainty Consider the option with the benefits that matter most to you and are most likely to happen. Avoid the options with the risks that matter most to you.

	Reasons to choose this option (Benefits / Advantages / Pros)		How much it matters (Use 0 to 5 ★s)		Reasons to avoid this option (Risks / Disadvantages / Cons)		How much it matters (Use 0 to 5 ★s)	
Option #1								
Option #2								
Option #3								

Which option do you prefer?

☐ #1 ☐ #2 ☐ #3 ☐ Unsure

Support

Who else is involved?

Option you think this person prefers?

☐ #1 ☐ #2 ☐ #3 ☐ Unsure

What role do you prefer in making the choice?

☐ Share the decision with ☐ Share the decision with
☐ Decide myself after hearing views of ☐ Decide myself after hearing views of
☐ Someone else decides ☐ Someone else decides

Who?

It's not always easy to reconcile the decisions that young people and their families make. The Ottawa Family Decision Guide is a great tool to insure that both the parent and the young person have a chance to review options and share what matters most with the team.

In closing, there is no doubt that shared decision making is a critically important approach for teams working with young people and their families.

SELF QUIZ – CHAPTER 3

Q. *Which of the following statements is true?*

- A. Young people tend not to want to be involved in the decision making process, especially if they don't make the final decision**
 - B. Shared decision making helps people feel respected because they have a voice and a choice in their care.**
 - C. Taking medications or not taking medications are the only options in medication consultations.**
-

Q. *Which of the following is an important consideration associated with shared decision making?*

- A. Young people complain of being left out of decisions or being talked about like they are not even in the room.**
 - B. Many young people desire parental involvement in decision making**
 - C. Young people tend to focus on short term quality of life factors, particularly side effects**
 - D. All of the above**
-

Q. *Which is NOT an important consideration when using shared decision making with young people?*

- A. Cognitive processes associated with decision making are still developing in younger adolescents**
- B. Young individuals are often non-compliant by nature**
- C. Triadic decision making often comes into play**

DISCUSSION QUESTIONS – CHAPTER 3

Use the following questions/statements to guide your discussion:

- Think of a time you struggled with speaking up during an appointment. How would shared decision making have helped you?
- Do you work with someone who feels their opinion isn't respected? How does that affect their care?
- Have you experienced a time when the individual being helped and their family had diverging opinions about the next steps in treatment? Describe. What did you do that helped or hindered?

- How do you personally convey the idea that recovery is real? At what point in treatment do you introduce recovery?
- How do you deal with families who are not supportive of a loved one getting help from your team?
- Can you think of a time watchful waiting would have been beneficial to a person you're working with? Explain.
- Identify a time in your experience as a clinician when using the Designated Observer worksheet would have been helpful.
- How might you encourage someone who chooses a passive, "you are the expert" role, to become more active in care-related decisions? What sort of questions might help the person become more activated?

SUGGESTED RESOURCES – CHAPTER 3

Here is a listing of resources for further exploration on the topics covered in this chapter:

- **Young Minds:** Here is a UK site promoting the use of shared decision making with young people in psychiatry. This site describes how involving young people in decision making improved the clinical process
(http://www.youngminds.org.uk/training_services/vik/children_young_peoples_iapt/involving_young_people_in_cyp_iapt/session_by_session_monitoring/capa_shared_decision-making)
- **Young adults with type 1 diabetes prefer clinicians who engage in shared decision making:** This is a scholarly article showing that young people do want to have a voice in decisions about their care. (<http://www.dovepress.com/shared-decision-making-the-perspectives-of-young-adults-with-type-1-di-peer-reviewed-article-PPA>)
- **The Ottawa Personal and Family Decision Guides:** These guides can help individuals and families assess their decision making needs, plan next steps, and track progress.
(<https://decisionaid.ohri.ca/decguide.html>)
- **Ottawa Personal Decision Guide Tutorials:** Here is a series of short videos showing how the Ottawa Personal Decision Guide can be used by an individual, with an advisor
(https://decisionaid.ohri.ca/opdg_video.html)

Notes: _____

Chapter Four:

Decision Aids



Decision aids are carefully developed tools for people facing tough health care and social choices. Decision aids help people understand their options, sort out their values and preferences, and participate in a process of shared decision making with clinicians.

In this chapter, we will learn what decision aids are. We will also take a tour of decision aids that your team can use when working with young folks experiencing psychosis and their families. We can't possibly cover every decision aid in this short video so be sure to consult your Viewer's Guide for additional tips and resources.

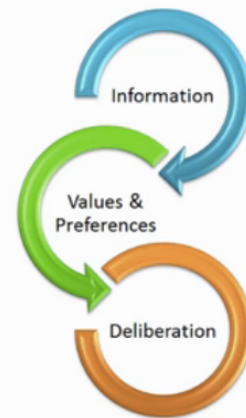
It's important to understand that decision aids and shared decision making are not the same thing. Shared decision making is a broader concept. It is possible to do shared decision making without a decision aid.

Decision aids, on the other hand, are tools that help people prepare to participate in shared decision making. Decision aids are adjuncts and are not meant to replace the important conversations that individuals have with clinicians.

Three Core Elements

Decision aids usually have three core elements.

- Up-to-date information about the choice an individual is facing, including options, and benefits and risks of those options.
- Values clarification exercises that help individuals sort out what matters and how various options may impact quality of life.
- Guidance for deliberation. For instance some decision aids have balanced first person narratives or videos. Others have a place to request more information, request input from family members, decisional leaning scales, interactive exercises, and the like.



Types of Decision Aids

Decision aids come in many formats including:




- Simple pen and paper tools
- Video formats with worksheets
- Issue cards
- Board games
- Websites
- Web applications

Marketing Bias and Evaluation Standards

Importantly, decision aids are not, and should never be developed by industry. It's important that decision aids do not are free of marketing bias. The International Patient Decision Aid Standards Collaboration – called IPDAS for short – develops standards for decision aid development and offers clear guidelines for evaluation of them.

At the Ottawa Hospital Research Institute, you can find an A to Z listing of decision aids. Here is an example of a Decision Aid called *Antipsychotic Medicines for Children and Teens: A review of the research for parents and caregivers*.

Decision Aid Summary

Title	Antipsychotic Medicines for Children and Teens: A Review of the Research for Parents and Caregivers
Health condition	Mental Disorders
Type of decision aid	Treatment
Options included	Aripiprazole. Clozapine. Olanzapine. Paliperidone. Quetiapine. Risperidone. Ziprasidone.
Audience	Parents and caregivers of a child or teen considering antipsychotic medicines.
Developer	Agency for Healthcare Research and Quality (AHRQ)
Where was it developed?	http://www.ahrq.gov/info/customer.htm Agency for Healthcare Research and Quality (AHRQ) US
Year of last update or review	2012
Format	Web, paper, audio, PDF
Language	English, Spanish
How to obtain	The AHRQ website. Available here.
The assessment (based on IPDAS) of this decision aid indicates that it meets:	
	8 out of 11 of the content criteria
	3 out of 9 of the development process criteria
	0 out of 2 of the effectiveness criteria

This contains a good summary of the decision aid, and a list of the medication options it presents. It was developed by AHRQ or the federal Agency for Healthcare Research and Quality. It comes in a variety of formats including the web, PDF and audio which actually reads the PDF if literacy is an issue. Note that this decision aid is also available in Spanish and English. You can also see how it scores on IPDAS standards. A convenient hyperlink is provided directly to the decision aid. Be sure to explore this site as you gather decision aids for use with young people and families served by your team.

How Are Decision Aids Used?

Decision aids can be used in 3 important ways.

- They can be used directly in the consultation
- They can be used outside of the consultation by individuals and families in an effort to get prepared for shared decision making
- They can be used in novel, socially mediated situations such as telephonic health coaching, peer2peer online sites, health navigators, and the like.




The first two options – decision aids for use within the consultation and prior to the consultation - are most relevant for teams working with young folks with psychosis.

Decision Aids and Consultation

Now we will look at two types of decision aids that have been carefully crafted for use within a consultation. These decision aids work like scaffolding to support a shared decision making conversation during actual face-to-face consultations.

The first is the *Option Grid for employment*.



Employment and mental health Use this grid to help you and your healthcare provider talk about the benefits and risks of staying off work or looking for paid work.		
Frequently asked questions	Continue to stay off paid work	Taking steps to go back to paid work with the help of an employment specialist (see note 1 below)
Does being at work make a difference to my health?	Research shows that being off all types of work for more than 6 months leads to poor health, both physical and mental. The longer you are not working, the higher the risks to your health.	Going back to any type of work is good for your physical and mental health and helps prevent you from becoming unwell again. It can undo the harm caused by being out of work for a long time. Research has shown that paid work improves income, use of time, motivation, confidence and self-esteem, and leads to better emotional well-being. Jobs that match your skills, and where employers support you, are good for your mental health.
What are the benefits?	For most people, there are no benefits to being off all types of work for more than 6 months.	You are 3 times more likely to get paid work with help from an employment specialist. They can advise you on many challenges such as talking about your mental health condition with potential employers and work colleagues. They can also help you deal with the worry of starting work, as well as concerns about the nature of your mental health condition, previous drug use, or a criminal record affecting your ability to get a job.
What are the risks?	It is difficult to predict how symptoms change, so waiting until you feel well increases the risk of never getting back to work. The more time you spend out of paid work, the harder it is to start. You risk losing your confidence, feeling isolated, and becoming anxious about losing your skills and knowledge. You might also feel awkward if asked to explain a work gap to an employer.	You may feel stressed or anxious that returning to paid work will reduce any government benefits you get because you are unemployed, or that you will have to talk about your mental health condition with an employer. An employment specialist and your health provider will help you deal with these concerns.
What are my choices?	If you don't feel ready for paid work, you can consider other work activities, for example, studying, volunteering, or caring for somebody. Talk to your health provider about your work goals and ask them to make a note of them in your treatment plan. There is plenty of evidence supporting that not working does not benefit either your physical or mental health. Before deciding not to work at all, you might want to talk to an employment specialist.	If you want to go back to paid work, you can be referred to an employment specialist. They will help you match your preferences, experiences, and strengths to jobs. Many people start by working part-time and find that part-time work suits them. Others move to full-time, with or without support from the employment specialist.
How soon can I return to work?	Does not apply.	You can make plans to return to paid work as soon as you want to do so. You don't have to wait for your symptoms to get better. An employment specialist will usually help you start your job search within four weeks of you first contacting them.

The option grid for employment is meant to be used when people face a decision about returning to work. In the first column are frequently asked questions such as “Does being at work make a difference to my health?” In the second column is an evidence based answer for the option of staying out of work. In the third column is an evidenced based answer for the option of going back to work with support from an employment counselor. You can just imagine how helpful this decision aid would be if you were working with a young person and/or family who felt uncertain about return to work after a diagnosis of psychosis.

The second type of decision aid created specifically for use within a consultation, are *Issue Cards*.



These are developed by the Mayo Clinic Shared Decision Making National Resource Center and are available for free. Two sets of Issue Cards may be especially helpful for teams serving folks with early psychosis. The first is the Diabetes Medicine Decision Aid and the second is the Depression Medication Choice.

Here's how they work:

Imagine that a practitioner and individual have decided in favor of a trial on an antidepressant. However, now the individual faces a decision about which one to use. Using the Depression Medication Choice decision aid, the practitioner would hold up the cards and ask which issue might be a top concern in choosing an antidepressant: Weight change: Approach to stopping; Sleep; Cost; or Sexual issues. The individual selects the Weight Change card. Scanning the card, it's obvious that desvenlafaxine is weight neutral when compared to some of the other antidepressants. Next, the individual would select a second card. This time it's the Sexual Issues Card. As you can see, desvenlafaxine may result in mildly lowered libido, making the individual less enthusiastic about this option. And so the process would continue.

Can you see how this decision aid is very engaging? It's all about the conversation and is not meant to replace the consultation. Instead, the decision aid acts as scaffolding to support a deeper conversation between the individual, the family and the practitioner.

A second category of decision aids, are those that can be used prior to the meeting with the clinician. They allow individuals and families to prepare to participate in shared decision making during the consultation. Remember, never just hand a decision aid to someone. Always remind people to review the decision aid and to return for the next appoint to talk things over.

First Person Narratives

Decision making is not just a rational process. Sorting through our emotions and being able to imagine various futures for ourselves is a critical part of decision making. Toward this end, first person narratives can be very helpful.



One great place to find first person accounts of psychosis and recovery is at the Center for Practice Innovations website (<http://practiceinnovations.org/>). Here you will find hope-filled, 3 minute videos from young people in recovery from early psychosis, and their families.

RECOVERYlibrary (<http://www.recoverylibrary.com>) is a site I put together. It has hundreds of videos of individuals describing their recovery from mental illness, physical health conditions and addiction. It also has lots practical recovery tools.



A fascinating site is called Health Talk (<http://www.healthtalk.org/>). It's a very reliable resource out of the UK. Of particular note is an entire section on young people's experiences. There is a section on eating disorders, and a section on cannabis use and mental health conditions. There are also some good videos from young people with psychosis.

Decisional Balance Worksheet

I hope you are feeling encouraged by these wonderful decision aids. Of course, there will never be a decision aid for every tough choice that people face. Because of this, the more generic decisional balance worksheet has been developed. There is a version for use with individuals and another for use with individuals and families together.

We live in exciting times where the dream of truly person centered care can become a reality. You can be part of making that dream come true by effectively involving folks in the use of decision aids and shared decision making.

SELF QUIZ – CHAPTER 4

Q. Which of the following is *NOT* a core element of a Decision Aid?

- A. Guidance for deliberation
 - B. Developed by the pharmaceutical industry
 - C. Up to date information
 - D. Values clarification exercises
 - E. All are core elements of decision aids
-

Q. Is the following statement True or False?

- All decision aids should be completed with a clinician.
-

Q. Which of the following are examples of decision aids?

- A. Simple pen and paper tools
- B. Video formats with worksheets
- C. Issue cards
- D. Board games
- E. Websites
- F. Web applications
- G. All of the above

DISCUSSION QUESTIONS – CHAPTER 4

Use the following questions/statements to guide your discussion:

- Why is it important for decision aids to be free from bias?
- Explore the A to Z listing of decision aids (<https://decisionaid.ohri.ca/AZlist.html>). Choose a decision aid, and discuss.
 - When, in your work, would this aid be useful?
 - Is there a person you are working with that could benefit from this decision aid?
- Watch this video of a practitioner using the Depression Choice Card (<https://www.youtube.com/watch?v=SpIgYmywdfM&feature=youtu.be>), and discuss.
 - How could this card be useful in your work?
 - When, in your work, would this Issue Card be useful?
 - Is there a person you are working with that could benefit from this Issue Card?

- Watch this video of a practitioner using the Diabetes Medication Choice Card (<https://www.youtube.com/watch?v=SYTPqceFgSw>) and discuss.
 - How could this card be useful in your work?
 - When, in your work, would this Issue Card be useful?
 - Is there a person you are working with that could benefit from this Issue Card?
- What is the best way to deliver decision aids in your setting? On paper? On a tablet computer?
- What would you do if you had a high quality decision aid for a particular decision, but the person you were helping did not want to use it?
- Decision aids have been proven to be effective in helping people arrive at outcomes that are more concordant with their preferences and values. But if they are not used, they just become “dustware” on the shelf. How will you make the decision aids a routine part of your team’s workflow?

SUGGESTED RESOURCES – CHAPTER 4

Here is a listing of resources for further exploration on the topics covered in this chapter:

- **Health Talk** (<http://www.healthtalk.org/>) is a reliable resource out of the UK. Of particular note is an entire section on young people’s experiences. There is a section on eating disorders (<http://healthtalkonline.org/young-peoples-experiences/eating-disorders/eating-disorders-and-thought-patterns>), and a section on cannabis use and mental health conditions (<http://healthtalkonline.org/young-peoples-experiences/drugs-and-alcohol/mental-health-and-cannabis>). There are also some good videos from young people with psychosis (<http://healthtalkonline.org/peoples-experiences/mental-health/experiences-psychosis/topics>).
- **Decisional Balance Worksheet:** There is a version for use with individuals (<https://decisionaid.ohri.ca/docs/das/OPDG.pdf>) and another for use with individuals and families together ([http://www.cheo.on.ca/uploads/Decision Services/OFDG.pdf](http://www.cheo.on.ca/uploads/Decision%20Services/OFDG.pdf)). Here is a video demonstration (https://decisionaid.ohri.ca/opdg_video.html) of the use of the decisional balance worksheet.
- **The Ottawa Hospital Research Institute:** This is the home page for the Institute, which has done important work in the area of evaluating and standardizing decision aids. (<http://www.ohri.ca/home.asp>)
- **The OHRI listing of decision aids.** Here you can find summaries of, and links to, decision aids for a wide variety of health related decisions. (<https://decisionaid.ohri.ca/AZlist.html>)

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Chapter Five:

Doing Shared Decision Making

Shared decision making is more than loose clinical collaboration. It is a formal process of collaborative deliberation conducted by trained clinicians, supported by programmatic infrastructure to support the work.

In this chapter, we will explore how to do shared decision making.

Four Things Needed for Shared Decision Making

Shared decision making does not just happen by itself. Plans must be developed to support the routine practice of shared decision making on teams working with young people with early psychosis. There are 4 things we must do to get prepared.

- First, we begin by communicating the expectation that individuals and their families (or supporters) will routinely be involved in shared decision making. From day 1 individuals and family members should receive the message that they are part of the team, there is hope for recovery and the team needs folks to speak up and share their expertise in order to arrive at the best decisions about treatment and recovery.
- Secondly, clinicians on the team must be trained in shared decision making. Over time there will be staff turnover. Your team must have a plan to train new team members in shared decision making, including the use of the Decisional Balance Worksheet, the Designated Observer worksheet and the Ottawa Family Decision Guide.
- Third, it's important to put together a library of decision aids for easy access. Many decision aids are online and can be printed out. I suggest putting together a lending library for decision aids. Additionally, make a folder on your laptop or tablet with hyperlinks to the decision aids and recovery videos. Make index cards of web addresses of the recovery videos to give to families. They can watch them at home. Finally, make sure in-consultation decision aids, such as issue cards, are placed in clinicians' offices for easy access.
- Fourth, be sure to talk about how shared decision making can happen within your routine care pathway. Is there really time for shared decision making in the medication consultation? Can that process be streamlined by people reviewing decision aids prior to the consultation? Make a list of common decision points encountered by the folks you work with. How does shared decision making apply? How can shared decision making happen in the field vs. in the office? Should team members have tablets to make online content such as videos, easily available in the field?



3-Step Model

With regard to the practice of shared decision making, there are a number of practice models that overlap in significant ways. I am choosing to teach you a concise 3-step model developed by one of the world's foremost authorities on shared decision making, Glyn Elwyn.



As both an academic and a primary care physician who practices shared decision making, Dr. Elwyn teaches us that there are 3 basic steps in *doing* shared decision making:

Choice talk, Option talk and Decision talk.

These three steps happen within a context of collaborative deliberation that supports a person in moving from initial preferences, to informed preferences.

Step 1 in shared decision making is **Choice talk**. The goal of choice talk is making sure that people understand that choices exist. We don't want people making choices when they are insufficiently informed. The elements of choice talk include:

- Stepping back and making it clear to the individual and family, that a decision needs to be made and there is more than one option to consider. An example might be: there is a decision to be made about treatment for psychosis. There are options to consider such as watchful waiting, cognitive behavioral therapy or which, if any, medication to use.
- Next, we invite the individual and supporters to participate in making the decision. Don't be surprised if folks find this invitation unusual. If people are surprised, it can help to re-assure them that one size treatment does not fit all. There are pros and cons to each option and some will matter more individuals and family than others. Another great way to respond if folks act surprised is to say, "I need you to help me to understand what's right for you."
- Sometimes people will protest and say, "But you are the expert. Tell me what to do!" In such cases it's important to defer disclosure, but not leave the person feeling abandoned or alone with a tough decision. Dr. Elwyn suggests, "I'm happy to share my views and help you get to a good decision. But before I do so, I want to describe the options in more detail so you will understand what's at stake."



Step 2 in shared decision making is **Option talk**. Whereas choice talk is about making sure people know that options exist, option talk refers to providing more information about the options. Of course, decision aids can be a big help during option talk.

- Continuing along with our example, one good way to begin option talk is to say, "What have you heard about treatment for psychosis?" This gets people talking and allows you to begin to hear their initial preferences and/or misconceptions.



- The next step is to literally make a list of the options, including watchful waiting if relevant. Then turn the paper so folks can see the list.
- Next, begin discussing the pros and cons, benefits and harms of each option. Continuing our example, we would discuss the benefits and harms associated with using antipsychotics, adjusting for gender, ethnicity and age as much as possible. For watchful waiting and cognitive behavioral treatment we would do the same.
- The last step in option talk is teach back. Ask the person to verbally summarize what they have learned. Offer corrections as needed.

Step 3 in shared decision making is **Decision talk**. Decision talk refers to supporting the work of considering preferences and deciding what's best. Remember that decision making is not simply a rational process. Emotion is increasingly recognized as a critical component of human sense making. Continuing with our example of choice of treatment for psychosis, knowing the facts of each option is not enough. Part of the work is called affective forecasting or asking oneself, "What would the use of an antipsychotic be like *for me*?"

- The role of the clinician in decision talk is to facilitate deliberation. Some questions that help are:

- What's the hardest thing about deciding?
- Given what we've discussed, do you have a preference about our next step?
- Are you ready to decide? Do you want more time? Do you have more questions? Are there more things we should discuss? Are there other people you might want to talk with to sort things through?



- Clinicians practicing shared decision making must remember that deciding is a process and can take time. It might not happen in one consultation and that's OK. People will often want to take information away from the clinic and share it with important people in their lives. This is called a distributed deliberation process and is not uncommon. In such cases, be sure to arrange a next visit with the individual to review their thoughts and decisional leaning.
- Another strategy that can support the decision talk phase of shared decision making is to use reflective listening techniques and say, "Given what you and your family have been saying so far, I might suggest...How does that sound to you?"
- Finally, once a decision has been made, the decision must be implemented. As decision talk wanes, the conversation begins to focus on planning the next steps.

In summary, choice talk, option talk and decision talk are the 3 steps in shared decision making.

SELF QUIZ – CHAPTER 5

Q. *What are the 3 steps in shared decision making?*

- A. Choice talk, option talk and dialogue talk**
 - B. Choice talk, dispositional talk and decision talk**
 - C. Control talk, option talk and decision talk**
 - D. Choice talk, option talk and decision talk**
-

Q. *Is the following statement True or False?*

- **Decision talk refers to supporting the work of considering preferences and deciding what's best**
-

Q. *Which of these is NOT needed for shared decision making?*

- A. Clinicians must be trained in shared decision making**
- B. A collection of decision aids must be available**
- C. Discussions are held surrounding how shared decision making can happen in practice**
- D. An area is designated where shared decision making occurs**
- E. Expectations are communicated that individuals and their supporters will be routinely involved in shared decision making.**

DISCUSSION QUESTIONS – CHAPTER 5

Use the following questions/statements to guide your discussion:

- What will your team's shared decision making process look like? Beyond scheduled team meetings, how will team members stay in sync during specific deliberation processes?
- In a given situation, how will you know when it's time to transition between choice talk, option talk, and decision talk?
- If an individual or family does not initially want to be involved in shared decision making, how can you use these tools to bring them on board as part of the decision making team?
- What would a distributed deliberation process look like on your team? How would you document the process? How would you balance leaving enough time for deliberation with ensuring that a decision actually does get made and acted upon?

SUGGESTED RESOURCES – CHAPTER 5

Here is a listing of resources for further exploration on the topics covered in this chapter:

- **A scholarly article describing the choice talk, option talk, and decision talk model of shared decision making:** (<http://www.ncbi.nlm.nih.gov/pubmed/22618581>)
- **A document describing how to use choice talk, option talk, and decision talk with decision aids:** (http://personcentredcare.health.org.uk/sites/default/files/how_to_use_a_bda.pdf)
- **An overview of the shared decision making process:** This includes a rationale and descriptions, including a discussion of the continuum between paternalism and informed choice, and the three stages of shared decision making described in this chapter.
(<http://medical.cdn.patient.co.uk/decision-aid/what-is-shared-decision-making.pdf>)

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Chapter Six:

You are Part of the Team

When a car breaks down, we bring it to the repair shop to get fixed. The car doesn't have to do anything. It just sits there while the experts fix the problem. But things don't work that way if we have been diagnosed with psychosis. The experts who work with us can't fix us in the same way a mechanic fixes a car. Instead, the experts need us to speak up and help them find the treatment that's right for us.

I was diagnosed with schizophrenia when I was a senior in high school. Like many people, when I first came for help I was quiet and passive. I figured the doctors, nurses and social workers were the experts. I was afraid to ask questions because I thought I'd sound dumb. I remained quiet even if I disagreed with what the professionals were recommending. I was afraid speaking up would seem disrespectful. This strategy did not work very well for me and I ended up overmedicated, out of school and depressed about my lack of progress.

In order to recover and get the life I wanted for myself, I had to get active. I had to speak up. I learned the professionals on my treatment team could not read my mind. They needed to hear about what mattered to me. I began to understand that my family and I were also experts. We were experts in who I was as a unique individual. We were experts in my history and what my dreams, goals and aspirations were. I was the expert on which medication side effects were tolerable and which ones were not. In other words, I learned that when I met with my doctor or social worker, there were two experts in the room. When all the experts worked together, we got the best results for my recovery.

Now that you are coming for help, you will notice the professionals on your team will not make all the decisions for you. Instead, they will invite you to be involved in something called "shared decision making". Shared decision making means having a voice and choice in your treatment. This may seem a bit strange at first. You might find yourself thinking, "Hey, you are the expert. Tell me what to do." If you have this reaction, you are not alone. It feels new and different when professionals invite us to participate in shared decision making. But stick with it. In the long run, having a voice and choice in your treatment will help you recover and get the life you want for yourself.

What to Expect

- First, you'll be working with a team of professionals. Your team will probably include a team leader, an employment and education specialist, a recovery coach, and a psychiatrist and/or nurse. Importantly, your team won't be complete until you and your family joins as well.

- Think of it this way: you'll only spend a few hours a year in the office, at meetings with your team. Most of your recovery will happen outside of the office, in the context of your everyday life. Did you know we spend about 5,000 waking hours outside of the mental health clinic every year? Your team can't possibly be with you during all those hours. It's up to you and your family to continue practicing what you are learning about recovery, in those other 5,000 hours of your life. That's why I really mean it when I say you are part of the team.
- Second, your team practices shared decision making. That means you can expect they will:
 1. Make it clear when a decision needs to be made
 2. Explain your options and,
 3. Support your decision making

Let's look a bit more closely at these three steps so you know what to expect.

Step 1: Your team will be very clear with you when a decision needs to be made. Here are some common decision points you might encounter:

- Deciding which medication might be right for you
- Deciding to return to school or to start a job
- Deciding when it's time to move on from the program

Additionally, you may be facing a decision the rest of your team does not know about. For instance:

- You might be thinking about going off a medication
- You might have heard about a new all natural vitamin treatment that you want to try
- You might be considering having a baby



If you are facing decisions like this, tell your team. They won't make the decision for you. Instead they will support you in sorting things out and making the decision that's right for you.

Step 2: Once you and your team know a decision needs to be made, they will help you understand your options. For instance, if you are faced with a decision about which antipsychotic medicine to try, you should expect your doctor to explain your options including the potential benefits and harms of the different medications. Your doctor or nurse will want to hear your thoughts and discuss any concerns you may have. Here are some good questions to ask:

- What other options, besides medicine, do I have?
- What happens to people who don't use the medicine?
- How might this medicine help me do the things that are important to me?

- What are the side effects?
- How much is the co-pay for each of these meds?
- How will I know if this medicine is working for me?
- How might this medicine affect my sex drive or my energy level?
- How might this medication affect my health?
- How long will it take for this medicine to begin working for me?
- How can I get in touch with you if I have concerns about this medicine?



When considering your options, your team might offer you a decision aid. Decision aids can be written documents like the one you see here. Decision aids can also be videos or websites like the ones you see here. Decision aids explain more about the decision you are facing, your options, the benefits and harms, and decision aids will help you clarify what matters most to you. You can take the decision aid home, review it with people you trust and return to your next appointment more empowered to discuss your preferences with the team.

Step 3: Once you have learned about your options, your team will support you in arriving at a decision. You can expect they will say things like:

- What, from your point of view, matters most as you consider these options?
- What's the hardest thing about deciding?
- Given what we've discussed, do you have a preference about our next step?
- Are you ready to decide?



You don't have to feel pressured to make a decision right away. It's OK to take time to consider your options. It's also OK to invite your family or other important people in your life, to review information with you.

In shared decision making, there are no right or wrong answers. Your team has the goal of helping you make the decision that is right for you.

Recovery is real and I wish you the best on your journey of recovery.

SELF QUIZ FOR INDIVIDUALS AND FAMILIES – CHAPTER 6

Q. *Is the following statement true or false?*

- **You are part of the treatment team.**

Q. *Is the following statement True or False?*

- **You should tell your team if you have concerns about taking a medication or want to try an alternative therapy.**
-

Q. *Which of the following is NOT a step in the shared decision making process?*

- A. **Making it clear when a decision needs to be made**
- B. **Explaining your options**
- C. **Supporting your decision making**
- D. **Deciding whether your decision was right or wrong**

DISCUSSION QUESTIONS – CHAPTER 6

Discussion questions for individuals:

- In what areas are you and your family the experts on your shared decision making team? In what areas are the professionals the experts?
- How might you communicate your ideas about the pros and cons of using a medication a professional on your team?
- Why is it important for you to speak up about what matters most to you as you make medication decisions during your recovery?
- Would you involve your family in a decision about a medication change? Why or why not?
- Would you feel comfortable asking for a decision aid to help you think through the options of a care-related decision that you were facing?
- How would you handle a professional who approached you as if decisions had already been made for you? How would you invite the provider to practice shared decision making?

Discussion questions for family members:

- What is your role when your loved one is considering stopping or starting the use of an antipsychotic medication?
- How might you participate in a period of watchful waiting if your loved one decides to try a period of time without antipsychotic medication?

- Can you be an effective liaison between your loved one and his or her care team as important decision points, such as going back to school or work, arise?
- Research shows that young people are more focused on short term quality of life, whereas family members are more focused on long term outcomes. How can you take this into account when participating in shared decision making with your loved one?

Discussion questions for OnTrack teams:

- How will you incorporate the video for this chapter into your workflow so as to activate individuals and family members as part of the shared decision making team?
- How might you handle a situation where a family member or individual said, “You decide for me”?
- How will you motivate individuals who are reluctant to participate in shared decision making?
- How might you handle an overbearing family member who disrupts the shared decision making process by taking up most of the time?

SUGGESTED RESOURCES – CHAPTER 6

Here is a listing of resources for further exploration on the topics covered in this chapter:

- **An article in Health Affairs:** showing that people who are actively involved in their health care decisions tend to have better outcomes
(http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=86)
- **BMJ Quality and Safety:** This is an article describing a process for measuring how well professionals involve individuals in decision making
(<http://www.ncbi.nlm.nih.gov/pubmed/12679504>)
- **An article advocating more involvement by care-receiving individuals in medical decision making:** (<http://www.medicalnewstoday.com/articles/261078.php>)

Notes: _____

Appendix A: Answer Sheet

INTRODUCTION

Q. *Is the following statement true or false?*

- **Shared decision making is primarily for medication decisions and psychiatrists will predominantly use this practice in the work of OnTrack teams.**

A. *The answer is:*

- **False.**
-

Q. *Is the following statement true or false?*

- **Shared decision making is a unique practice and should not be combined with other evidence based practices such as motivational interviewing and family psycho education.**

A. *The answer is:*

- **False.**
-

Q. *Is the following statement true or false?*

- **Most person centered clinicians already practice shared decision making.**

A. *The answer is:*

➤ **False.**

CHAPTER 1

Q. *Which of the following statements is true?*

- A. Persuasion has a limited place in the shared decision making process
- B. Shared decision making should be used in situations where there is more than one right choice
- C. Decision aids are patient education aids
- D. Decision aids are best used in clinic settings, such as shared decision making centers
- E. Therapists and case managers have fewer opportunities to practice shared decision making when compared to medical practitioners

A. *The answer is:*

➤ **B.**

Q. *Which of the following outcomes has not been found in studies of shared decision making?*

- A. Lower levels of satisfaction
- B. Higher levels of patient engagement
- C. Lower healthcare costs
- D. Less decision regret
- E. Reduction in preference misdiagnosis
- F. All of the above

A. *The answer is:*

➤ **A.**

Q. *Which of the following statements is inaccurate?*

- A. Shared decision making is an ethical imperative in all situations in which individuals are faced with a medical decision
- B. When a woman on mood stabilizing medications becomes pregnant, the decision to use/not use medications is a preference sensitive decision
- C. Shared decision making should be used when someone has an acute life-threatening condition
- D. Shared decision making is perfected informed consent
- E. Decision regret is typically higher when decision aids are unavailable

A. *The answer is:*

- A.
-

CHAPTER 2

Q. *Which of the following scenarios reflect a preference sensitive decision?*

- A. The decision to use or not use psychiatric medicine
- B. The decision to undergo ECT
- C. The decision to use an antidepressant medication with fewer sexual side effects over another
- D. The decision to return to school
- E. All of the above

A. *The answer is:*

- E.
-

Q. *Is the following statement True or False?*

- Shared decision making does not apply to people under a court order for compulsory treatment.

A. *The answer is:*

- False

Q. Which of the following scenarios demonstrates a crossroad decision point?

- A. The decision to increase the dose of an antidepressant
- B. The decision to use psychiatric medications during pregnancy
- C. The decision to complete an application for a job
- D. The decision to take a full course load for fall semester, or to take one class that semester.
- E. 1 and 2

A. The answer is:

- B.

Q. Is the following statement True or False?

- Someone who is experiencing acute positive symptoms of psychosis can never participate in shared decision making due to decision incapacity.

A. The answer is:

- False

CHAPTER 3

Q. Which of the following statements is true?

- A. Young people tend not to want to be involved in the decision making process, especially if they don't make the final decision
- B. Shared decision making helps people feel respected because they have a voice and a choice in their care.
- C. Taking medications or not taking medications are the only options in medication consultations.

A. *The answer is:*

➤ **B.**

Q. *Which of the following is an important consideration associated with shared decision making?*

- A. **Young people complain of being left out of decisions or being talked about like they are not even in the room.**
- B. **Many young people desire parental involvement in decision making is still viewed as desirable by many**
- C. **Young people tend to focus on short term quality of life factors, particularly side effects**
- D. **All of the above**

A. *The answer is:*

➤ **D.**

Q. *Which is NOT an important consideration when using shared decision making with young people?*

- A. **Cognitive processes associated with decision making are still developing in younger adolescents**
- B. **Young individuals are often non-compliant by nature**
- C. **Triadic decision making often comes into play**

A. *The answer is:*

➤ **B.**

CHAPTER 4

Q. Which of the following is *NOT* a core element of a Decision Aid?

- A. Guidance for deliberation
- B. Developed by the pharmaceutical industry
- C. Up to date information
- D. Values clarification exercises
- E. All are core elements of decision aids

A. The answer is:

- B.
-

Q. Is the following statement True or False?

- All decision aids should be completed with a clinician.

A. The answer is:

- False.
-

Q. Which of the following are examples of decision aids?

- A. Simple pen and paper tools
- B. Video formats with worksheets
- C. Issue cards
- D. Board games
- E. Websites
- F. Web applications
- G. All of the above

A. The answer is:

- G.

Q. *What are the 3 steps in shared decision making?*

- A. **Choice talk, option talk and decision talk**
- B. **Choice talk, option talk and dialogue talk**
- C. **Choice talk, dispositional talk and decision talk**
- D. **Control talk, option talk and decision talk**

A. *The answer is:*

- **D.**
-

Q. *Is the following statement True or False?*

- **Decision talk refers to supporting the work of considering preferences and deciding what's best**

A. *The answer is:*

- **True.**
-

Q. *Which of these is NOT needed for shared decision making?*

- A. **Clinicians must be trained in shared decision making**
- B. **A collection of decision aids must be available**
- C. **Discussions are held surrounding how shared decision making can happen in practice**
- D. **An area is designated where shared decision making occurs**
- E. **Expectations are communicated that individuals and their supporters will be routinely involved in shared decision making.**

A. *The answer is:*

- **D.**

CHAPTER 6

Q. *Is the following statement true or false?*

- **You are part of the treatment team.**

A. *The answer is:*

- **True.**

Q. *Is the following statement True or False?*

- **You should tell your team if you have concerns about taking a medication or want to try an alternative therapy.**

A. *The answer is:*

- **True.**
-

Q. *Which of the following is NOT a step in the shared decision making process?*

- A. **Making it clear when a decision needs to be made**
- B. **Explaining your options**
- C. **Supporting your decision making**
- D. **Deciding whether your decision was right or wrong**

A. *The answer is:*

- **D.**

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